AUGUST 7, 2013 MINUTES
PATIENT CHOICE AND MEANINGFUL DISCLOSURE WORKGROUP:
MEANINGFUL DISCLOSURE AT THE HIE WEBSITE SUBGROUP OF THE
GOVERNING BOARD OF THE ILLINOIS HEALTH INFORMATION EXCHANGE
AUTHORITY

The Illinois Health Information Exchange Authority, pursuant to notice duly given, held a meeting of the Meaningful Disclosure at the Health Information Exchange of the Patient Choice and Meaningful Disclosure Workgroup at or around 10:00 a.m. on August 7, 2013 at the James R. Thompson Center, 100 W. Randolph St., Chicago, Illinois 60601, with video and telephone conference call capability.

Particpant Name	Participant Representation
Danny Kopelson	Office of Health Information Technology
Glenn Susz (by phone)	APP Design
Howard Lee	Wirehead Technology
Jodi Sassana	MCHC MetroChicago HIE

- Subgroup Introduction: Subgroup chair, Danny Kopelson, introduced himself to the subgroup and asked the participants in the meeting to do the same.

- Participant Introduction: All present members introduced themselves, the organizations they represented, and their interest in health information exchange. Glen Susz participated via telephone.

- Danny Kopelson began the meeting by reviewing the action plan and defining the meeting's objectives: to define the scope and content of meaningful disclosure regarding health information exchange at the level of the HIE website, identify issues of the health information exchange that should be addressed on an HIE website, and develop resources for consumers at the HIE website and for providers at the point of care to ensure that patients receive meaningful disclosure about HIE and their rights with respect to the disclosure of their PHI via an HIE to other providers or third parties.

  o Deliverables: An explanation of the purposes of an HIE, audio, visual, and written instructions of how to opt out of an HIE.

  o Content Required: Each HIE will establish a publically accessible website containing an explanation of the purposes and potential uses of an HIE, audio, visual, and written instructions of how to opt out of an HIE, and the fact that the HIE will disclose patients' health information unless the patient opts out of the process.

  o Form of Disclosure: HIEs may develop additional educational content explaining the opt out policy including signs, posters, brochures, pamphlets, Q and A, etc.

- Danny Kopelson incited discussion by recapping the subgroup's previous meeting. ILHIE's website (and the kind of information being provided there) was heavily discussed.

  - Howard Lee shared his opinions of the ILHIE.org with the subgroup. Howard Lee not only read and downloaded the available information, but shared it with colleagues. Howard raised questions to the subgroup concerning the intended audience. Is the site intended to be more consumer friendly or more provider friendly?

  - Danny Kopelson explained that up until now it has primarily been used by professionals, stakeholders in HIE. Moving forward it will have as much of that role, if not more with more providers signing on, but the site has become more consumer driven than it has ever been. Danny explained that because it is a state site there are certain restrictions and a standard format.

  - Howard Lee raised the topic of connecting the ILHIE page to a social media platform. How involved should the consumer be?

  - Danny Kopelson explained that social media is not in their mandate. It will be up to the ILHIE Authority how they will approach this in the future. It is his impression that they develop the information necessary to inform consumers of patient consent. Educating consumers of what HIE is and their rights are in the sense of privacy, security and opting in and out.

- The goals, role and granularity of the subgroup were discussed. What is the subgroup trying to accomplish and what precedents are they trying to set.

- The subgroup discussed other state's sites. The brevity of New York's site was discussed. Many states are doing the bare minimum that is mandated. Following the lead of other states may be helpful. The simplicity of West Virginia's form was brought to the subgroup's attention.

- Danny Kopelson explained Protected Health patients to the subgroup and what that means in terms of opt in, opt out. The subgroup discussed in great detail opting in and out, Breaking the Glass and patients with HIV/AIDS and/or mental illnesses.

- The audio/ visual aspects of the ILHIE site were discussed. What should be included on the site and in what kind of detail? Again, other state's sites were examined and compared to Illinois'. What materials will be created and how and to who will these materials be distributed?

- The subgroup brainstormed on whether it would be worth considering having a link on provider websites that referred patients to the educational material on the ILHIE website since patients would be more likely to visit their providers' websites instead of ILHIE's.

- As in the previous meeting, a Participant suggested that the ILHIE should create a standardized graphic to be distributed among providers. A regulated and consistent message would be beneficial.

- In conclusion of the meeting all subgroup members agreed, again, that they would review other state's web pages and provide feedback for the ILHIE website for the next meeting.